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501(C)(3) Veterans Non-Profit

ANNUAL LEGISLATIVE PRESENTATION

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NATIONAL PRESIDENT

PARALYZED VETERANS OF AMERICA

BEFORE A JOINT HEARING OF THE

HOUSE AND SENATE COMMITTEES ON VETERANS' AFFAIRS

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Chairman Tester, Chairman Bost, Ranking Member Moran, Ranking Member Takano, and members of the committees, I appreciate the opportunity to present Paralyzed Veterans of America's (PVA) 2024 policy priorities. For more than 75 years, PVA has served as the lead voice on a number of issues that affect severely disabled veterans. Throughout the years, we have championed critical changes within the Department of Veterans Affairs (VA) and educated legislators as they have developed important policies that impact the lives of paralyzed veterans.

Today, I come before you with our views on the current state of veterans' programs and services, particularly those that impact our members—veterans with spinal cord injuries and disorders (SCI/D). Access to VA's specialized systems of care is the center of their universe because they rely on it perhaps more than any other group of veterans served by the VA.

BACKGROUND—Our organization was founded in 1946 by a small group of returning World War II veterans, all of whom were treated at various military hospitals throughout the country as a result of their injuries. Realizing that neither the medical profession nor the government had ever confronted the needs of such a population, these veterans decided to become their own advocates and to do so through a national organization.

From the outset, PVA's founders recognized that other elements of society were neither willing nor prepared to address the full range of challenges facing paralyzed individuals, whether medical, social, or economic. They were determined to create an organization that would be governed by the members themselves and address their unique needs. Being told that their life expectancies could be measured in weeks or months, these individuals set as their primary goal to bring about change that would maximize the quality of life and opportunity for all people with SCI/D.

Over the years, PVA has established programs to secure benefits for veterans; reviewed the medical care provided by the VA's SCI/D system of care to ensure our members receive timely, quality care; invested in research; promoted education; organized sports and recreation opportunities; and advocated for the rights of paralyzed veterans and all people with disabilities. We have also developed long-standing partnerships with other veterans service organizations (VSO).

PVA, along with the co-authors of The Independent Budget (IB)—DAV (Disabled American Veterans) and the Veterans of Foreign Wars of the United States (VFW), continue to present comprehensive budget and policy recommendations to influence debate on issues critical to the veterans we represent. We recently released our budget recommendations for the VA for fiscal years (FY) 2025 and 2026 advance appropriations.[1]

VA's SCI/D SYSTEM OF CARE

VA's SCI/D system of care is a hub and spoke model. The 25 SCI/D centers are the hubs. Each center has highly trained and experienced providers including doctors, nurses, social workers, therapists, psychologists, and other professionals who can address the unique problems that affect veterans with SCI/D. Operations at these facilities are still rebounding from restrictions imposed during the COVID-19 pandemic. Masking is still required in some inpatient and outpatient SCI/D units and visitor restrictions are reinstated whenever there is a COVID outbreak on the unit. Throughout the past year, PVA encouraged facilities to increase recreational opportunities through the centers and return to the practice of open dining. Many facilities took our recommendations to heart and are making changes that will improve the physical and mental health of SCI/D patients.

I would be remiss if I didn't note that none of the 25 SCI/D centers are operating at full capacity, primarily due to personnel shortfalls. Many SCI/D-qualified nurses and other staff left the department during the pandemic and rebalancing staffing levels is taking longer than we had hoped. Despite record-setting hiring last year, we continue to see the same staffing deficiencies at the SCI/D centers, year-after-year.

Staffing impacts every aspect of health care to include the quality of the care received by the patient and employee's safety and well-being. I encourage you to monitor VHA's hiring practices closely so veteran patients are not adversely affected. With this in mind, we are deeply concerned with the Veterans Health Administration's (VHA) decision to severely limit hiring in 2024. Recent reports from the field tell us what is actually occurring at their facilities is a tantamount to a hiring freeze, meaning critically needed positions at SCI/D centers may continue to go unfilled.

My statement addresses several specific priorities we hope you will pursue this year but it is not inclusive of every area of concern for our members. Some interests not covered here include the implementation of the PACT Act (P.L. 117-168), access to VA dental care, improved employment opportunities for veterans with catastrophic disabilities, as well as the status of VA's electronic health record modernization. We continue to work on these and other areas of interest for paralyzed veterans and the broader veterans community.

We appreciate that the committees have always worked together in a nonpartisan way to address the needs of America's veterans, and PVA looks forward to working with you on matters of mutual concern.

[1] Independent Budget Recommendations for the Department of Veterans Affairs for FY 2025-2026

PVA PRIORITY: PROTECT ACCESS TO VA'S SPECIALIZED HEALTH CARE SERVICES

PVA firmly believes VA is the best health care provider for disabled veterans. The VA's SCI/D system of care provides a coordinated life-long continuum of services for veterans with SCI/D that has increased the lifespan of these veterans by decades. VA's specialized systems of care follow higher clinical standards than those required in the private sector. Preserving and strengthening VA's specialized systems of care—such as SCI/D care, blind rehabilitation, amputee care, and polytrauma care—remains the highest priority for PVA.

Staffing Vacancies—Caring for veterans with SCI/D requires sharp assessment, time- and labor-intensive physical skills, and genuine empathy. Nurses who work in SCI/D must possess unique attributes and specialized education. All Registered Nurses, Licensed Practical Nurses (LPNs), Certified Nursing Assistants (CNAs), and Nurse Practitioners working with the SCI/D population are required to have increased education and knowledge focused on health promotion and prevention of complications related to SCI/D. This includes the prevention and treatment of pressure injuries, aspiration pneumonia, urinary tract infections, bowel impactions, sepsis, and limb contractures.

The VHA hired 61,000 new employees in fiscal 2023, outpacing its goal by 17 percent and giving it a workforce of more than 400,000 for the first time. Despite their hiring successes and the flexibility gained by workforce provisions in the RAISE Act (P.L. 117-103) and PACT Act, nothing in the SCI/D system of care shows ongoing improvement in staffing levels. Staffing shortfalls continue to have a direct, adverse impact on the SCI/D system. Some facilities are capping admissions due to insufficient numbers of SCI/D nurses while they work to find qualified individuals to fill vacancies. One VA SCI/D center has not had access to a plastic surgeon for at least two years now nor is there one available in the community. This meant some veterans were denied admission to the unit if extensive wound care treatment was needed. The SCI/D Coordinator would attempt to locate other VA SCI/D hubs that would accept them while non-SCI/D providers, the center's lone wound care nurse, and augmenters from other departments were left to manage countless other urgent cases. Another facility desperately needs a psychiatrist and this vacancy has led to substantial delays in providing essential psychiatric care and services to veterans with SCI/D.

During their annual visits to each of the 25 SCI/D Centers, PVA's medical services team identifies critical vacancies at each facility and then provides that information to VA's leadership. Totaling in the hundreds, VA agrees with roughly 80 percent of our recommendations but only a fraction of them are filled. Too often at VA we see "staffing on a wire," an unstable practice of maintaining just enough staff to handle beds, but not enough to adapt to changing life events like staff illnesses and injuries. VA should staff each SCI/D center to the levels prescribed in VHA Directive 1176.[2]

Depending on the function level of an acute SCI/D patient, a nurse may spend an hour or more each time they enter a veteran's room doing physical transfers, repositioning, wound care, feeding assistance, bowel and bladder care, and other tasks. Nurses in other areas of work may be in and out of a patient's room in a matter of minutes. Despite the increased care that veterans with SCI/D require, not all SCI/D nursing staff (including LPNs and CNAs) receive specialty pay, which often elevates turnover rates.

Offering competitive pay isn't the only problem. If VA is not able to quickly hire high quality employees, it will lack the staff needed to accomplish its mission. VA staff often speak of the need for VA to better support continuing education requirements and advanced learning. Improvements in this area would greatly help VA's retention efforts.

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[2] VHA Directive 1176 (2), Spinal Cord Injuries and Disorders of Care

Additionally, VA's hiring process moves at a glacial pace, prompting many qualified individuals to accept employment in the private sector. VA has been scrutinizing the process used for credential checks, introductory paperwork, and other pre-work requirements for quite some time now. The time to reduce unnecessary burdens is now so the process is streamlined as much as possible.

The PACT Act and the RAISE Act gave the VA new pay and bonus authority to recruit in-demand health care workers but we know that more needs to be done. Passage of S. 10, the VA CAREERS Act, would give the VA the additional tools needed to allow the department to better compete for the highly qualified medical personnel it needs to care for catastrophically disabled veterans.

Infrastructure—VA's SCI/D system of care is comprised of 25 acute care centers and six long-term care centers ranging in age from three to 70 years with an average age of 38. Many of the older centers have only had cosmetic or basic renovations. Fourteen of the 25 acute care SCI/D centers continue to use four-bed patient rooms, accounting for 61 percent of the available in-patient beds. These four-bed patient rooms do not meet VA requirements and are no longer safe due to infection control issues. This high percentage of four-bed patient rooms limits available bed capacity whenever patients need to be isolated.

Furthermore, the number of long-term care beds for veterans with SCI/D is woefully inadequate for an aging veteran population with care needs not readily met in the community. Only one of VA's six specialized long-term care facilities lies west of the Mississippi River. Until construction projects at the Dallas and San Diego VA Medical Centers are completed, only 12 long-term care beds are available for the thousands of SCI/D veterans that reside in this area of the country.

The SCI/D system of care is not immune to the design and construction delays inherent in the VA project funding and delivery system. There are currently six major and nine minor SCI/D center projects either awaiting funding, in design, or pending approvals to proceed beyond their current status. VA has spent a significant amount of money and resources on these projects, most of which have languished within the department's Strategic Capital Investment Planning process. Also, replacement SCI/D center projects designed for the Bronx VA (acute) and the Brockton VA (long-term) intended to modernize and expand capacity were shovel-ready but abandoned by the VA.

In reviewing VA's infrastructure, decisionmakers must remember that VA's SCI/D system of care is unique and not replicated outside of VA. The VA SCI/D system of care provides a coordinated, life-long continuum of services for SCI/D veterans that is often unmatched anywhere in the community.

PVA believes that VA should return to the past practice of placing greater emphasis on funding facilities that support the types of services, like SCI/D care, which the department uniquely provides. Greater investment in areas like SCI/D care would greatly strengthen VA's specialty care services and ensure their future availability.

Even with a comprehensive strategy and adequate infrastructure funding, VA's internal capacity to manage a growing portfolio of construction projects is constrained by the number and capability of its construction management staff. To manage a larger, more complex capital asset portfolio, VA must have sufficient personnel with appropriate expertise—both within VA's Central Office and onsite throughout the VA system.

PVA strongly supports the Build, Utilize, Invest, Learn and Deliver (BUILD) for Veterans Act of 2023 (H.R. 3225/S. 42), which seeks to improve staffing to manage construction of VA assets and ensure that there are concrete plans to improve the planning, management, and budgeting of VA construction and capital asset programs.

I also want to thank you for approving language in the fiscal year 2024 National Defense Authorization Act (NDAA) that increased the threshold for VA's minor medical care facility construction projects. The new $30 million minor construction cap better reflects current construction costs and will allow local VA medical centers to complete projects more efficiently and cost-effectively to better serve our catastrophically injured and ill veterans with SCI/D. Additionally, the law now empowers the VA to adjust the minor construction cap in the future based on construction cost data. This will help the VA adjust construction budgets to avoid future delays of sorely needed veteran-centric projects that PVA has prioritized and advocated for to improve veteran's health care and safety inside all VA SCI/D centers. This issue was specifically raised by PVA's architects as a barrier to projects moving forward and the added funding for minor construction projects is an important step forward in getting veterans the much-needed care they deserve.

Finally, PVA strongly supports passage of the Veterans Accessibility Act (H.R. 7342/S.2516) to ensure that VA complies with federal disability laws and makes its programs accessible for people with disabilities. The bill would establish a 15-person Advisory Committee on Equal Access, which would consist of veterans with disabilities, disability experts, and representatives of advocacy organizations. The committee would be responsible for evaluating and reporting on VA's compliance with federal disability laws and would issue recommendations for how VA can improve its accessibility for people with disabilities. It would also examine the physical accessibility of VA facilities, as well as the accessibility of technology such as websites and apps.

Access to Inpatient Mental Health and Substance Use Disorder Treatment—It is a well-established fact that depression is closely associated with poor health outcomes and exposure to higher pain levels often trigger depression among members of the SCI/D community. Having a history of mental illness or substance abuse, current mental illness other than depression, and current abuse of alcohol or illegal substances are also risk factors for depression among the SCI/D community. Substance use disorders (SUD) are prevalent and associated with poor outcomes in individuals with SCI/D, with 14 percent of individuals with SCI/D reporting significant alcohol-related problems and 19.3 percent reporting heavy drinking. Large studies of U.S. veterans and Canadian citizens with SCI/D found that 55 to 79 percent were prescribed opioids, and low-quality evidence shows that risk of opioid misuse is higher in individuals with an SCI/D than in those without. It is estimated that 35.2 percent of individuals with an SCI/D use opioids daily, and that 17.6 to 25.8 percent self-report significant misuse of pain medications. Risk factors for SUD include having paraplegia versus tetraplegia, chronic pain, and low income. [3]

Suicide is a significant issue among our nation's veterans. In U.S. studies, individuals with SCI/D were reported to be three to five times more likely to die of suicide than were those in the general population; however, data for those injured in the last two decades are limited. One study reported a decreasing trend of suicide mortality in SCI/D cohorts from the 1970s to the 1990s, but the observed suicide rate was still at least three times that of the general population even in the later cohorts. Suicidal ideation is common after an SCI/D. Over 13 percent of an SCI/D cohort reported suicidal ideation in the prior two weeks in a cross-sectional analysis, and 7.4 percent reported a lifetime suicide attempt. Studies in non-U.S. populations also found increased suicidal ideation and suicidal attempts in individuals with SCI/D. While the injury or disorder in of itself increases suicide risk, higher risk of death by suicide after SCI/D has been associated with certain demographic (non-Hispanic White race) and injury characteristics (paraplegia, T1-S3 level with American Spinal Injury Association Impairment Scale A, B, or C), as well as a history of drug abuse or current alcohol abuse. [5] In cases where VA mental health or SUD inpatient care is not available, it is provided in alternative VA settings with adequate safety precautions (e.g. one-to-one level of observation) and strong mental health consultation services, or in non-VA settings by referral.

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[3] Bombardier, C. H., Azuero, C. B., Fann, J. R., Kautz, D. D., Richards, D. S., & Sabharwal, S. (In Publication). Management of Mental Health Disorders, Substance Use Disorders, and Suicide in Adults with Spinal Cord Injury. Washington, DC: Paralyzed Veterans of America.

PVA believes it is in the best interest of our members that VA develop national procedures and protocols related to providing mental health and SUD inpatient care for veterans with SCI/D and that information on VA inpatient care for these veterans be tracked and reported.

Title 38 Protections for Community Care—PVA remains deeply concerned about the exclusion of protections for injuries that occur as a result of community care. Title 38 U.S.C. § 1151 protects veterans in the event that medical malpractice occurs in a VA facility and some additional disability is incurred or health care problems arise by providing clinical appeal rights, no-cost accredited representation, and congressional oversight and public accountability. However, if medical malpractice occurs during community care, the veteran must pursue standard legal remedies, and is not privy to VA's non-adversarial process. If these veterans prevail on a claim, they are limited to monetary damages instead of enjoying the other ancillary benefits available under Title 38 intended to make them whole again. Congress must ensure that veterans who receive care in the community retain current protections unique to VA health care under 38 U.S.C. § 1151.

PVA PRIORITY: EXPAND ACCESS TO VA'S LONG-TERM SERVICES AND SUPPORTS

Insufficient Long-Term Care Beds and Services for Veterans with SCI/D—Our nation's lack of adequate long-term care options presents an enormous problem for people with catastrophic disabilities who, because of medical advancements, are now living longer. There are very few long-term care facilities that are capable of appropriately serving veterans with SCI/D. VA operates six such facilities; only one of which lies west of the Mississippi River. All totaled, the department is required to maintain 198 authorized long-term care beds at SCI/D centers to include 181 operating beds.

As of last month, only 169 beds were actually available. This number fluctuates depending on several variables like staffing, women residents, isolation precautions, and deaths. When averaged across the country, that equates to about 3.4 beds available per state. Many aging veterans with SCI/D need VA long-term care services but because of the department's extremely limited capacity, veterans sometimes remain in the acute setting for months or years at a significant cost because other placements are simply not available. Others must reside in nursing care facilities outside of VA that are not designed, equipped, or staffed to properly serve veterans with SCI/D. As a result, veterans staying in community nursing facilities often develop severe medical issues requiring chronic re-admittance back into an acute VA SCI/D center.

VA has identified the need to provide additional SCI/D long-term care facilities and some of these requirements have been incorporated in a pair of construction projects but most of their plans have been languishing for years. In 2021, work began on a replacement acute SCI/D care facility in San Diego that will add 20 new long-term care beds into the system. This construction project is on schedule to open for patient care in early 2025.

Construction of a new long-term care SCI/D center at the VA North Texas Health Care System in Dallas began in January 2024. If everything stays on track, this facility, which is designed to include 30 SCI/D long-term care beds, will be completed in the spring of 2027. The North Texas project also includes shell space for an additional 30 long-term care beds and would provide shared resident dining, kitchen, and living areas to support them, as well as common resident gathering areas and space to support staff on that level. Completing the additional 30 beds would take relatively little effort as the building will already be completed, yet there is currently no funding to support building out the shell space. The need for long-term care beds is particularly severe in the south-central region as there is not a VA SCI/D long-term care center within 1,000 miles of Dallas despite a significant regional population of veterans with SCI/D. Not funding this project postpones the opportunity to further address the shortage of VA long-term care beds for the aging population of veterans with SCI/D.

Additional projects at Brockton, MA, and Bronx, NY, would have added more than 100 additional long-term care beds to VA's inventory but they were set aside in 2012 and 2014 (respectively) even though their project designs were 65 percent complete. Three other projects at Long Beach, CA; St. Louis, MO; and Tampa, FL, would renovate existing facilities that currently house acute and long-term care SCI/D beds. We urge Congress to provide the necessary funding to construct the additional 30 long-term care resident beds at the VA North Texas Health Care System, and allow the other five projects I just mentioned to resume or progress. Also, Congress should direct VA to reassess its current SCI/D long-term care capacity and future SCI/D long-term care needs so adequate resources can be authorized and appropriated.

In addition to ensuring access to VA provided SCI/D long-term care, we support expanding access to assisted living options. Currently, the VA can refer veterans to assisted living facilities, but it cannot directly pay for that care. PVA strongly supports the Expanding Veterans' Options for Long Term Care Act (H.R. 1815/S. 495), which would create a three-year pilot program at six Veterans Integrated Service Networks (VISN), including at least two program sites in rural areas and two in State Veterans Homes to test the benefit of having VA pay for this care. Veterans eligible for the pilot would include those already receiving nursing home-level care paid for by the VA and those who are eligible to receive assisted living services or nursing home care. At the conclusion of the pilot program, participating veterans will be given the option to continue receiving assisted living services at their assigned site, paid for by the VA. We believe this would help veterans and the VA alike by giving greater access to assisted living and reducing costs for long-term care, allowing more veterans to receive needed assistance.

Improve Availability of VA's Home and Community-Based Services (HCBS)—I'd like to commend the House on last year's passage of the Elizabeth Dole Home Care Act (H.R. 542), which would make critically needed improvements to VA HCBS, such as lifting the department's cap on the amount they can pay for home care, increasing access to the Veteran Directed Care (VDC) Program and improving support to caregivers of veterans. At the same time, I don't believe I can properly articulate our members disappointment that this critical legislation has not yet become law. I understand this legislation is to be included in a larger package of legislation that is currently being considered by Congress, but I cannot stress enough how important it is to get these provisions enacted into law now.

As reported by the VA, veterans over the age of 85 are the fastest-growing segment of the veteran population. Further, the number of veterans eligible for nursing home care is projected to increase 535 percent, from 62,000 to 387,000, over the next 20 years. The current cost to the VA for nursing home care alone is not sustainable. Alternative home care supports and assisted living offer significant cost savings for veterans who don't require a high level of medical care. A 65-year-old today has almost a 70 percent chance of needing some type of long-term care services and supports in their remaining years and will need it for an average of three years. Twenty percent are projected to need long-term care for five years or more. For those who will need long-term care, costs will average $138,000 annually for these services. Costs to care for an SCI/D veteran would be much higher than that. Although VA has identified the need to construct additional SCI/D long-term care facilities, they have not sought funding for them even as the number of veterans who need access to these facilities increases.

Despite doubling HCBS spending between 2016 and 2021, VA still spends just over 30 percent of its long-term care budget on HCBS, which remains far less than Medicaid's HCBS national spending average for these services among the states. Congress and the VA must work together to ensure that funding and accessibility catches up with and then keeps pace with the demand for these essential services.

Furthermore, the VA is currently prohibited from spending on home care more than 65 percent of what it would cost if the veteran was provided nursing home care. When VA reaches this cap, the department can either place the veteran into a VA community living center or a community nursing home facility or rely on the veteran's caregivers, often family, to bear the extra burden. Depending on the services available in their area, some veterans must turn to their state's Medicaid program to receive the care they need, even for service-connected disabilities.

Amyotrophic lateral sclerosis (ALS) is presumptively related to military service and is rated by the VA at the 100 percent level. And yet, we are aware of many ALS veterans who are not receiving proper home care. Andrew, who served in the Air Force and has been living with this horrific disease for 14 years, is currently bed-bound, paralyzed, non-verbal due to a tracheostomy, on a ventilator, and enteral nutrition-fed. His wife Lisa has had to work hard to secure the equipment and services needed to keep her husband alive and comfortable at home. Now, they are forced to consider giving up VDC in lieu of the Family Caregiver Program, because expenses related to Andrew's care were projected to exceed the cap later this year. This disruption in the continuity of his care should be totally unnecessary, and highlights the need to eliminate the cap, so veterans like Andrew can receive the care he needs. Also, Lisa is at a point in her life where her presence may be needed elsewhere. Her mother was recently diagnosed with cancer and she would like to be able to accompany her children as they explore college opportunities. Knowing that the VA would provide full coverage would allow her to step away to address these important life events.

It isn't just ALS veterans who are impacted by this cap. A 40-year-old SCI veteran who is tracheostomy dependent has been in a facility since 2019 due to the cost of his care. He has a 11-year-old daughter that he cannot see often because of this. Another veteran with a form of multiple sclerosis who has a gastrostomy tube, a tracheostomy and is ventilator dependent is on the verge of ending up in a facility. His family needs 8 hours of care per day on the weekdays but VA is only able to approve 16 hours per week due to costs. Congress needs to pass the Elizabeth Dole Home Care Act to allow the VA to cover the full cost of home-based care services for these veterans and others like them without exhausting their caregivers and leaving them struggling to cobble together the services and supports they need to stay home with their families.

***VDC Program*—**PVA strongly believes that the VA and Congress must make HCBS more accessible to veterans. One of the programs that should be expanded to all VA medical centers is the VDC Program. The VDC program allows veterans to receive HCBS in a consumer-directed way and is designed for veterans who need personal care services and help with their activities of daily living (ADL). Examples of the types of assistance they can receive include help with bathing, dressing, or fixing meals. VDC also offers support for veterans who are isolated, or whose caregiver is experiencing burden. Veterans are given a budget for services that is managed by the veteran or the veteran's representative.

Unfortunately, the VDC program is still not available at all VA medical centers and it currently has an enrollment of only about 6,000 veterans. Even though VDC is available at a facility, it doesn't always mean that it is available for veterans throughout the facility's catchment area. Our members and other veterans are constantly asking for help in getting this program implemented at their VA medical care facility. In past years, my predecessors have spoken about Milton, a PVA member who has been waiting more than five years for the Cleveland VA to implement the program. I'm pleased to report that Milton's long wait ended last month when he was the first veteran in Stark County, Ohio, to be enrolled in the program. Now, he has greater control of his care, and the ability to choose direct care providers that he trusts.

Even if the program is available at a particular facility, veterans—*and the staff*—may not be aware of it or given the opportunity to enroll. VA needs to do a better job of educating staff and veterans about the program, and veterans should be given the choice to access it where it is available. While the department is in the process of expanding its VDC program to all VA medical centers, the increase of actual participants has been nominal. We urge Congress to provide the necessary funding so every VA medical center can offer a robust VDC program as quickly as possible.

***Address Direct Care Workforce Shortages*—**I consider myself to be extremely lucky to have my wife as my primary caregiver. For more than 30 years, LaShon has been at my side to offer me the care I need and her prolonged presence has been a source of great comfort to me. Some PVA members do not have family members close by or their physical needs are so great that they must secure direct care workers to support them in home and community settings. Anne, an Army veteran and PVA member is a good example. In October 1999, while deploying on a training exercise to Fairbanks, Alaska, she sustained an SCI as a result of a military vehicle accident and since that time has been a quadriplegic. Her spouse, Harry, has been her primary caregiver but Anne's physical needs are so great they also rely on direct care workers to help provide the care she needs. Finding the right candidate who understands the unique nature of the job and possesses the right combination of hard and soft skills to help her proved to be a formidable challenge.

Direct care workers provide a wide range of supportive services to veterans with SCI/Ds including habilitation, health needs, personal care and hygiene, transportation, recreation, housekeeping, and other home management-related supports, so veterans can live and work in their communities and live productive lives. Finding the right candidate who understands the unique nature of the job and possesses the right combination of hard and soft skills to help her proved to be a formidable challenge. She was forced to interview over 100 applicants because most weren't experienced with specialized care or physically strong enough to care for her. She is lucky in a way because she resides in a major metropolitan area so at least there are candidates to interview. However, she hasn't been able to find any appropriate candidates recently.

The shortage of caregivers or home care workers is not unique to the VA. Across the country, there is an increasing shortage of direct care workers, and a national effort is needed to expand and strengthen this workforce. I share these stories to emphasize how precarious the HCBS/long-term care system is and how the lack of home care providers is adversely impacting the care and quality-of-life of veterans with SCI/D. Veterans with disabilities have the right to quality care in their homes.

Increasing the amount veterans can pay for essential caregivers is a necessary component of attracting and retaining a diverse set of people to provide HCBS but raising pay alone is not sufficient to solve the crisis we face. Utilizing multiple strategies, such as raising public awareness about the need and value of caregiving jobs, providing prospective workers quality training, and developing caregiving as a sound career choice are a few of the other changes that could help turn this problem around. On a national level, Congress could consider establishing a College Service Corps that provides incentive bonus awards to college students who agree to serve as a direct care worker for a specific timeframe. Meanwhile, the VA should develop a pilot program that retains the former caregivers of veterans to care for other veterans. These individuals are familiar with the unique needs of veterans and the many nuances of the VA healthcare system making them a provider of choice for other disabled veterans.

Finally, last year, PVA voiced concerns about veterans with catastrophic disabilities having to rely on their caregiver during hospitalization, and if they are enrolled in the VDC Program, when the veteran is hospitalized, VDC payment is discontinued until the veteran is discharged from hospital care. Neither community hospitals nor VA medical centers are adequately staffed or trained to perform the tasks veterans with SCI/D need.

Prior to April 2023, veterans with high-level quadriplegia and other disabilities were required to pay out of pocket for their caregivers or caregivers donated their time, as veterans could not receive caregiving assistance through VA programs while in an inpatient status. PVA raised this issue to the attention of VHA's Geriatric and Extended Care (GEC) national program office. Last year, GEC issued guidance to the field stating if a veteran is assigned Case Mix "V" or who has a score of "K" they may continue to receive VDC services during inpatient hospitalization, if it is clinically indicated and in support of the veteran's care needs. The Case Mix Tool is specifically designed to assist clinicians in determining the appropriate budget to best support veterans' home care needs.

While we greatly appreciated this change, it benefits a very limited number of veterans. Plus, it excludes many deserving veterans with catastrophic disabilities who rely on caregivers, but are not assigned into Case Mix "V" or have a score of "K." Many SCI/D veterans are still unable to receive payment for their caregivers when they are hospitalized. This limitation must be addressed as these veterans not only need their caregivers while hospitalized but also to ensure that they can be timely discharged home.

Assistance for Family Caregivers—Executing the Program of Comprehensive Assistance for Family Caregivers (PCAFC) continues to be challenging for the VA. As of January 1, 2024, the VA reported having 10,460 applications in process, but the department is no longer reporting the number of approved applications. Instead, they are reporting the percentage of approvals reported by VISN. Without being able to track the number of applications approved in comparison to the number of pending applications it is difficult to keep track of their progress.

VHA is currently working on a rulemaking to make changes to the current caregiver regulation and an announcement about those proposals is expected soon. In the meantime, I would like to highlight several concerns that consistently pose challenges for our members in accessing and benefiting from this critical program to ensure you are aware of them.

First, we strongly believe that the PCAFC should be reformed to ensure that veterans' efforts to be independent, when possible, do not disqualify them from participating in this program. The current requirement for veterans to need assistance "each time" they perform an ADL[4] is overly restrictive and fails to recognize the reality of living with a catastrophic disability. As a result, veterans have been unjustly denied participation in the PCAFC. Instead, VA should adopt a less stringent requirement, such as "regularly requires" assistance.

In addition, we continue to be concerned by the requirement for veterans to have a 70 percent disability rating in order to be eligible for the PCAFC. As PVA noted in our May 2020 comments on the proposed rule, "the necessary VA rating should be lowered to 50 percent or more; or as combined with any other service-connected disability or disabilities for a combined rating of 50 percent or more. Congress believed that these veterans were of the highest concern, and assigned them to VA health care priority group one, which is the highest priority group a veteran can be assigned."[5] We firmly believe the current rating requirement is too restrictive as it has prevented many deserving veterans from being eligible for the program and it should be lowered to 50 percent. VA should also address the onerous criteria for assignment to the highest tier under the PCAFC. Veterans with significantly different levels of disability are assigned to the lowest tier, because of the overly restrictive criteria for the highest tier.

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[4] 38 C.F.R. § 71.15.

[5] Paralyzed Veterans of America, Comment Letter on Proposed Rule about the Program of Comprehensive Assistance for Family Caregivers Improvements and Amendments Under the VA MISSION Act of 2018 (May 5, 2020).

I'm in the PCAFC and was assigned the lowest tier. Out of curiosity, I asked a nurse in the program what it would take for a veteran to be placed in the higher tier. Essentially, she told me they would have to be bedbound and incoherent in order for that to happen.

VA's current requirement fails to recognize that veterans who are able to have a measure of independence still may need significant caregiver assistance in completing their ADLs. PVA raised this concern in our comments to VA's proposed rule in May 2020. We noted that, "Requiring a veteran to be fully dependent on a caregiver each time he or she completes three or more ADLs will result in few veterans being eligible for the higher-level stipend. VA should reconsider this requirement because it works against the department's efforts to foster veterans' independence wherever and whenever possible and promotes total reliance on a caregiver."[6] This concern has now become a reality and VA must remedy this problem when revising the PCAFC rule. In the alternative, VA should provide additional tiers to recognize the diversity of care needs and the burden on family caregivers.

***Codify VA's Bowel and Bladder Program*—**SCI/Ds can significantly impact a person's quality of life, and neurogenic bladder and bowel dysfunction are crucial aspects of their care. These conditions affect many veterans with SCI/Ds and can lead to complications, re-hospitalizations, and mortality. Therefore, managing neurogenic bladder and bowel requires specialized attention, as it can be costly, is unrelenting over time, often necessitates substantial caregiver support, and is essential for maintaining veterans' health and well-being.

VA's Bowel and Bladder program is administered by VHA's SCI/D National Program office. Veterans with SCI/D who qualify for bowel and bladder care may receive that care through a home health agency, a family member, or an individually employed caregiver. The clinic of jurisdiction, or VA medical facility, authorizes bowel and bladder care under the Office for Integrated Veteran Care (IVC), to enrolled veterans with SCI/D who are dependent upon others for bowel and bladder care while residing in the community. As soon as designated caregivers successfully complete training from the VA, all necessary forms are forwarded to IVC for sign off and approval of the authorization process. Additionally, the caregiver must obtain a National Provider Identifier, complete a Veteran Care Agreement (VCA), track the amount of time needed to perform the veteran's bowel and bladder care on a daily basis and submit it along with a VA Form 10-314, Request for Payment of Bowel and Bladder Services, to be reimbursed.

The current program is fraught with challenges for caregivers and is unevenly applied across the VA system. Timely reimbursement and the tax treatment of payments are the chief complaints of PVA members who must rely on bowel and bladder care to meet their needs. A good example is John, who provides bowel and bladder care for his wife Julie, an Army veteran who suffered a SCI/D in a car accident and is a paraplegic. Despite filing a recent reimbursement claim on time, VA's payment failed to materialize so he reached out to PVA for assistance. While trying to rectify the situation, we were told the delay stemmed from a requirement that payments over $1,000 require a second signature. Oddly, his monthly reimbursement payments have exceeded this level for the past two years and were not subjected to this same requirement.

Delays like this should not be taken lightly because of the adverse impact they have on the veteran and their family. In this case, delaying the flow of income into their home forced John and Julie to take money out of their savings to ensure their bills were paid.

Unlike virtually all other VA payments, including those provided through the PCAFC, Bowel and Bladder program reimbursements are taxable. Even family caregivers are considered federal contractors for providing this care

[6] *Id*.

and must pay self-employment tax. Harry, caregiver for his wife Anne, a PVA member, pays $3,500 to $3,700 in self-employment taxes each year. He figures he is probably making a quarter of what the VA would pay an agency to provide the care. Anne appreciates that her husband is able to provide her much better care than anybody else, but is disappointed that he is only receiving minimal pay to provide the life-sustaining care she must have on a regular basis due to her service-connected disability.

Another compelling reason to make the Bowel and Bladder program a statutory requirement is that the current program fails to offer veterans due process. There is no formal notification to the veteran, caregiver, or the provider that a VCA agreement is coming up on its three-year renewal and that it must be re-signed. Hence, due to the lack of notification, veterans and caregivers continue to file monthly claims and out of the blue payments stop and they don't know why. Getting the program reinstated is a tremendous challenge and due to lack of payment, the veteran may actually lose the caregiver. The whole process starts all over again, with the veteran having to find, train, and formally designate a caregiver which can take weeks to months to complete this process; putting the veteran with SCI/D at risk due to not receiving timely bowel and bladder care. In similar fashion, a veteran or caregiver are not notified if they file a monthly claim that has errors or missing information nor how to correct them. They just simply don't get paid and it is up to the veteran or caregiver to reach out to the IVC to find out why.

The Bowel and Bladder program is a life-sustaining program providing support to veterans with SCI/Ds. Codifying the program would allow Congress to finally resolve the tax burden and delayed payments for family members who perform bowel and bladder care. And as principal users of the program, we hope that Congress and the VA will provide PVA ample opportunity to "shape" the program's language.

PVA PRIORITY: IMPROVE VA BENEFITS AND HEALTH CARE SERVICES FOR PARALYZED VETERANS AND THEIR SURVIVORS

Special Monthly Compensation (SMC) Aid and Attendance Rates—There is a well-established shortfall in the rates of SMC paid to the most severely disabled veterans. SMC represents payments for "quality of life" issues, such as the loss of an eye or limb, the inability to naturally control bowel and bladder function, the inability to achieve sexual satisfaction, or the need to rely on others for ADLs like bathing or eating. To be clear, given the extreme nature of the disabilities incurred by most veterans in receipt of SMC, PVA does not believe that a veteran can be totally compensated for the impact on quality of life, however, SMC does at least offset some of that loss. Many severely disabled veterans do not have the means to function independently and need intensive care on a daily basis. They also spend more on daily home-based care than they are receiving in SMC benefits.

One of the most important SMC benefits is Aid and Attendance (A&A). Securing the services of a direct care provider is very expensive and often the A&A benefits provided to eligible veterans do not cover this cost. Many PVA members who pay for full-time attendant care incur costs that far exceed the amount they receive as SMC beneficiaries at the R-2 compensation level (the highest rate available).

Ultimately, they are forced to progressively sacrifice their standard of living in order to meet the rising cost of the specialized services of a trained caregiver; expensive maintenance and certain repairs on adapted vehicles, such as accelerated wear and tear on brakes and batteries that are not covered by prosthetics; special dietary items and supplements; additional costs associated with needed "premium seating" during air travel to decrease the chance of injury in boarding and deplaning; and higher-than-normal home heating/air conditioning costs in order to accommodate a typical paralyzed veteran's inability to self-regulate body temperature.

Likewise, SMC fails to account for the cost of ordering things when the in-person pickup option is not accessible, building a wheelchair ramp, acquiring and maintaining service animals, buying a more expensive car in order to accommodate a larger power wheelchair, purchasing food for special diets, or paying more for housing in order to find a place that is accessible and convenient. Oftentimes, veterans are forced to dedicate more and more of their monthly compensation to supplement the shortfalls in the A&A benefit, it slowly erodes their overall quality of life and can lead to health issues.

Both SMC and A&A are subject to annual cost-of-living increases but the formula used to establish the increase often understates the actual rate of increase in goods and services required by these individuals. Also, the baseline rates have not been examined by Congress in years. We urge the Committees to review and subsequently increase the rates of SMC and A&A soon to ensure these benefits meet the needs of veterans, their spouses, surviving spouses, and parents.

Military Sexual Trauma (MST)—During the 117th Congress, several bills were passed that improved processes for the survivors of MST. The MST Claims Coordination Act (P.L. 117-303) ensures improved communication and engagement between the Veterans Benefits Administration and the VHA which will assist survivors in accessing mental health support and improve the benefit filing experience. This should reduce gaps in care during the claims process.

While this law should improve the process, there is still plenty of work to be done. Per the Department of Defense's (DOD) Annual Report on Sexual Assault for FY 2022, 8.4 percent of active-duty women and 1.5 percent of active-duty men experienced unwanted sexual contact. It is important to highlight that those figures account for almost 36,000 servicemembers, all of whom might seek benefits and services from the VA due to MST.

With increasing numbers of servicemembers reporting unwanted sexual harassment, attention, and other behaviors experienced throughout DOD, Congress must pass H.R. 2441/S. 1028, the Servicemembers and Veterans Empowerment and Support Act of 2023, which expands the qualifying characteristics of MST, improves the benefits process, and increases access to health care for MST survivors.

Congress and the VA must continue to work with VSOs to identify gaps in support and ensure that all MST survivors are treated with dignity and respect. Because of the lasting psychological and physiological impacts of this trauma, it is critical that the VA fully train its MST coordinators and ratings officials to the sensitive nature of these claims as well as the range of issues and symptoms experienced with MST, particularly for veterans with complex injuries and illnesses.

Concurrent Receipt—The issue of concurrent receipt falls under the purview of the Armed Services Committees but it is closely linked with the VA Committees' efforts. A pair of changes approved by Congress in the mid-2000's allowed military retirees with over 20 years of service and VA disability ratings of 50 percent or greater to receive their military retired pay and VA disability compensation payments without offset. A lone exception to the 20-year requirement was granted for servicemembers retired under the Temporary Early Retirement Authorities Congress granted to the Department of Defense in the National Defense Authorization Acts for FY2012 and FY2017 (P.L. 112-81 and P.L. 114-328). Despite these reforms, thousands of military retirees continue to have their military retirement offset by VA disability payments today. Congress should pass legislation allowing all military retirees to retain their full military retired pay and VA disability compensation without any offsets.

Benefits for Surviving Spouses—Our oldest veterans are passing away and, in the case of many of our members, their surviving spouses were their primary caregivers for 40 years or more. Many of them were not able to work

outside of the home. When a service-connected SCI/D veteran passes away, monthly compensation that may have been upwards of $10,000 a month stops, and their surviving spouse receives roughly a fifth of that per month in Dependency and Indemnity Compensation (DIC), creating a tremendous hardship on those left behind. Adjusting to this precipitous drop of revenue into the household can be too difficult for some surviving spouses who may be forced to sell their homes and move in with friends or family members.

Losing a spouse is never easy but knowing that financial help will be available following the death of a loved one can ease this burden. DIC is intended to protect against survivor impoverishment after the death of a service-disabled veteran. In 2024, this compensation starts at $1,612.75 per month and increases if the surviving spouse has other eligible dependents. DIC benefits last the entire life of the surviving spouse except in the case of remarriage before a certain age. For surviving children, DIC benefits last until the age of 18. If the child is still in school, these benefits might go until age 23.

The rate of compensation paid to survivors of servicemembers who die in the line of duty or veterans who die from service-related injuries or diseases was created in 1993 and has been minimally adjusted since then. In contrast, monthly benefits for survivors of federal civil service retirees are calculated as a percentage of the civil service retiree's Federal Employees Retirement System or Civil Service Retirement System benefits, up to 55 percent. This difference presents an inequity for survivors of our nation's heroes compared to survivors of federal employees. DIC payments were intended to provide surviving spouses with the means to maintain some semblance of economic stability after the loss of their loved one.

PVA strongly believes the rate of compensation for DIC should be indexed to 55 percent of a 100 percent disabled veteran's compensation and we urge Congress to pass the Caring for Survivors Act of 2023 (H.R. 1083/S. 414), which would increase the rate of compensation for DIC payments to achieve parity with similar compensation federal employees' survivors receive

Additionally, if a veteran was rated totally disabled for a continuous period of at least eight years immediately preceding death, their surviving spouse can receive an additional amount (currently $342.46) per month in DIC. This monetary installment is commonly referred to as the DIC "kicker." Unfortunately, surviving spouses of veterans who die from ALS rarely receive this additional payment. ALS is an aggressive disease that quickly leaves veterans incapacitated and reliant on family members and caregivers. Many spouses stop working to provide care for their loved one who, once diagnosed, has an average lifespan of between three to five years; thus, making it very difficult for survivors to qualify for the kicker.

As previously stated, the VA already recognizes ALS as a presumptive service-connected disease, and due to its progressive nature, automatically rates any diagnosed veteran at 100 percent once service connected. The current policy fails to recognize the significant sacrifices these veterans and their families have made for this country and I urge Congress to pass the Justice for ALS Veterans Act (H.R. 3790/S. 1590) to provide the DIC kicker to eligible survivors of veterans who died of service-connected ALS.

Transportation Programs and Supports—Access to safe and reliable transportation is essential to the mobility, health, and independence of catastrophically disabled veterans, just like everyone else. Thus, addressing transportation concerns is a top priority for PVA. Transportation is the largest barrier to health care access to over five million veterans living in rural and urban areas and especially the catastrophically disabled. It is important to understand this because according to the VA, missed appointments cost the department over $4 billion per year and most are due to lack of transportation. That number may be higher since it probably didn't account for veterans who are not eligible for travel reimbursement. From an economic standpoint, missed

appointments set off a cascade of higher costs in the VA healthcare system, through the ripple effect created by patients with a higher risk of negative health outcomes to clinicians and medical assistants in rescheduling.

Several PVA members have received the additional automobile allowance approved by the last Congress as part of the Veterans AUTO and Education Improvement Act (P.L. 117-333). You have given them the means to not only purchase a new vehicle but also preserve their independence. We hope you would consider providing a similar auto allowance to veterans with non-service-connected catastrophic disabilities. Like those with service-connected disabilities, these veterans served honorably. They are eligible for VA health care and having access to an adapted vehicle helps them get to and from their appointments at the VA, particularly if they live in a rural area.

The Veterans AUTO and Education Improvement Act also changed the definition of "medical services" to include certain vehicle modifications (e.g., van lifts) offered through VA's Automobile Adaptive Equipment program. Specifically, it amended the definition of "medical services" under 38 U.S.C. § 1701(6) to include the provision of medically necessary van lifts, raised doors, raised roofs, air conditioning and wheelchair tiedowns for passenger use. The change was intended to codify VA's existing practice of furnishing certain items, like van lifts and wheelchair tiedowns to catastrophically disabled veterans. However, where the VHA has used these items as examples, the statute defines them as the only types of modifications that are permissible. Like the VA, we agree that a technical amendment to 38 U.S.C. § 1701(6) is needed to give the department greater flexibility in making the necessary modifications to veterans' vehicles to ensure they can safely enter, exit, or operate the vehicle and transport needed equipment, including power wheelchairs. The new law inadvertently limits the scope of an existing benefit and these changes better reflect the congressional intent of the original provision.

Even if they have access to an adaptive vehicle, some PVA members do not qualify for beneficiary travel when traveling to and from a VA medical facility for an appointment. A case worker recently shared with us that she has been working with an 85-year-old veteran paraplegic whose transportation issues have had a significant negative impact on his physical and mental health over the past 2-3 years. He is just over the income limit for VA funded travel and therefore has to try and find his own transportation to the VA for SCI/D care. County agencies are extremely limited in the help they can provide due to staffing issues, and his wife's ability to transport him is even more limited due to age and health related issues of her own. The veteran has missed a multitude of medical appointments, including those for pain management and outpatient physical/occupational therapy. His physical and mental health is rapidly deteriorating, to the point he is verbalizing symptoms of high anxiety, lack of sleep, depression and passive suicidal ideation. The VA referred him to mental health support groups and individual psychotherapy, however, the underlying problem of not having consistent transportation to the VA remains. His lack of transportation has clearly had a "snowball effect" on his health and unless the issue of his lack of access to transportation is addressed, his condition will continue to get worse.

In 2017, Congress amended the beneficiary travel rule to authorize travel for any veteran traveling with vision impairment, a veteran with a SCI/D, or a veteran with double or multiple amputations. To be eligible for beneficiary travel under this change, the travel must be in connection with care provided through a special disabilities' rehabilitation program of the department (including programs provided by SCI/D centers, blind rehabilitation centers, and prosthetics rehabilitation centers) and if such care is provided on an in-patient basis; or during a period VA provides the veteran with temporary lodging to make such care more accessible to the veteran. Unfortunately, the language of that amendment excluded catastrophic veterans from beneficiary travel when traveling to a special disabilities' rehabilitation program for outpatient services. Veterans, service officers, and VA staff consistently cite the lack of travel reimbursement as a major impediment for veterans to get the care they need. The exclusion of travel reimbursement for outpatient care may well have been a cost saving

move, but it results in higher health care costs for the VA and poorer health outcomes for veterans due to delayed treatment or diagnosis**.**

For those eligible for beneficiary travel, the rate of reimbursement is too low. Fourteen years ago, Congress passed legislation to set the mileage reimbursement rate at a minimum of $0.41 per mile which at the time was comparable to rates federal employees were reimbursed for work-related travel. This law also gave the Secretary the authority to increase rates going forward to be consistent with the mileage rate for federal employees for the use of their private vehicles on official business, as established by the Administrator of the General Services Administration (GSA). Since that time, VA's travel mileage reimbursement rate has remained stagnant, even while gas prices and other costs like auto insurance and vehicle maintenance costs have increased significantly. Meanwhile, GSA has increased its mileage reimbursement rates to 65.5 cents per mile. PVA urges Congress to pass the Driver Reimbursement Increase for Veteran Equity Act (DRIVE Act) (H.R. 1278/S. 522) to ensure VA's rate matches GSA's rate.

VA's Beneficiary Travel Self-Service System (BTSSS) also needs more attention. Launched in late 2020, the new cloud-based system was intended to improve the process for veterans to submit and track transportation reimbursements using VA's secure web based BTSSS portal. However, PVA members and other veterans routinely voice concerns over how difficult the system is to navigate. One member shared that the kiosks were removed from his clinic and replaced with QR codes. However, this veteran did not have a smart phone, so he was unable to access the portal when he needed it. Another member recently moved, and he was blocked from accessing the portal because his address didn't match VA records. When he tried to correct his information with the assistance of VA staff, they were still unable to gain access to the platform.

As VA modernizes and upgrades platforms and engagement methods, it is critical to remember that many veterans do not have equitable access to computers, broadband, and even smart phones. The traditional ways of accessing VA benefits are still necessary for our rural, low-income, disabled, and aging veterans. To ignore them and their needs, is not an option.

Finally, a robust network of public transportation such as buses, subways, and paratransit services for people with disabilities is often not available outside of urban areas. Truth be told, what is available within urban areas may not be suitable for SCI/D veterans either. VA's Veterans Transportation Service provides transportation to help veterans who live within a VA medical center's catchment area to get to and from medical appointments. Unfortunately, it is not available at all VA facilities and cannot help veterans who live beyond a certain distance of the medical center.
Passage of legislation like the Rural Veterans Transportation to Care Act (S. 3751) would help more veterans in rural areas get transportation to VA health facilities and access the health care benefits they've earned. The bill expands eligibility to the VA's Highly Rural Transportation Grant Program, which provides grant funding for VSOs and State Veterans Service Agencies to provide veterans transportation in eligible counties. It also increases grant rates to help organizations purchase a vehicle that complies with the Americans with Disabilities Act.
Many veterans have experienced travel delays and no shows for scheduled pick-ups with the systems that are available. Too often, their travel service is late in picking them up so they are late for appointments and forced to reschedule them. Also, there are times when the travel contractor never picks them up at all and they do not contact the waiting veteran, so they are forced to reschedule their travel and their appointment. Congress and the VA must work together to improve travel options for catastrophically disabled veterans, including those who live in rural areas.

Life Insurance Benefits—Congress passed a provision included in the Johnny Isakson and David P. Roe, M.D. Veterans Health Care and Benefits Improvement Act of 2020 (P.L 116-315) reforming the Service-Disabled

Veterans Life Insurance (S-DVI) program. The newly implemented Veterans Affairs Life Insurance (VALife) program provides guaranteed acceptance whole life coverage of up to $40,000 to veterans with service-connected disabilities. Lesser amounts are available in increments of $10,000. Under this plan, the elected coverage takes effect two years after enrollment as long as premiums are paid. If the veteran passes away during the two-year period, then premiums are refunded but no benefit is paid.

Requiring a two-year waiting period for full insurance coverage has a detrimental effect on veterans with ALS, because many do not live that long. The same issue applies to veterans with other terminal diseases, like service-connected cancers. Additionally, under SDV-I, veterans rated 100 percent service connected did not have to pay premiums. In 2023, under VALife, if a 100 percent service-connected veteran is 79 years old, the premium for a $20,000 policy would be $242.80, and for a $40,000 policy, it would be $485.60. If a veteran has a 50 percent disability and applies for a $40,000 policy, 45 percent of their monthly compensation would be taken to pay for insurance premiums. Congress must reinstate the premium waiver for veterans with 100 percent service-connected disabilities and waive the two-year contestability period for veterans with ALS and other service-related disabilities. Additionally, there is no form to complete for VALife, the only way to apply is online. This can be a significant challenge for catastrophically disabled veterans and VA should consider increasing the number of ways interested veterans can apply for the program. VA's lack of compliance with website accessibility standards[7] supports our belief that additional application options are necessary.

Home Modification Grants—Improvements are long overdue for VA's Home Improvements and Structural Alterations (HISA) program. HISA grants help fund improvements and changes to an eligible veteran's home. Examples of qualifying improvements include improving the entrance or exit from their homes, restoring access to the kitchen or bathroom by lowering counters and sinks, and making necessary repairs or upgrades to plumbing or electrical systems due to installation of home medical equipment. A lifetime HISA benefit is worth up to $6,800 for veterans who need a housing modification due to a service-connected condition. Veterans who rate 50 percent service connected may receive the same amount even if a modification is needed due to a non-service-connected disability. Veterans who are not service connected but are enrolled in the VA healthcare system can receive up to $2,000.

These rates have not changed since 2010 even though the cost of home modifications and labor has risen more than 50 percent during the same timeframe. As a result, that latter figure has become so insufficient it barely covers the cost of installing safety bars inside a veteran's bathroom. Congress needs to pass legislation, such as the Autonomy for Disabled Veterans Act (H.R. 2818/S. 3290) or the Autonomy for All Disabled Veterans Act (H.R. 4047) to raise HISA grant rates and index the grant to account for inflation and increased construction costs.

Health Care and Benefits for Women Veterans—Among the veteran population, women are the fastest-growing cohort. Women veterans, including those with SCI/D, need access to comprehensive, gender-specific care, services, and support that meet them where they are. The VA should be providing the highest standards of care when it comes to quality, privacy, safety, and dignity. The VA has a robust SCI/D system of care to serve the needs of veterans with SCI/D, but there needs to be greater collaboration with SCI/D centers and gender-specific care for our women veterans.

PVA is pleased with the increased funding that Congress provided for gender-specific care and programs in VA's FY 2023 budget and encourage you to carefully track how the department is using this funding. This would help

[7] VA Should Enhance Its Oversight to Improve the Accessibility of Websites and Information Technology Systems for Individuals with Disabilities (vaoig.gov)

ensure the funds are being used for gender-specific care, and guarantee that women veterans with SCI/D are not ignored when it comes to resource allocation. Considerable progress was made in the last Congress with the passage of the MAMMO Act (P.L. 117-135), and the SERVICE Act (P.L. 117-133), but other accessibility issues across the VA system of care still need to be addressed. VA needs to do an assessment of accessible medical diagnostic equipment to ensure that all veterans have the same access to health care and services. Exam room tables and chairs and imaging equipment may be inaccessible for non-ambulatory veterans.

As VA and Congress work together to oversee the implementation of accessible medical equipment across the system, PVA asks for transparency and cooperation from both. PVA would also like to stress that while women veterans may be the fastest growing cohort of veterans, and per the VA they comprise 30 percent of new VA users, the average age of a woman veteran is from 55-62, meaning that the average woman veteran needs increased menopausal care and other resources for aging women.

Assisted Reproductive Technologies (ART)—Recognizing the need for ART options, Congress granted temporary authorization in 2016 for the VA to provide in vitro fertilization (IVF) to veterans with a service-connected condition that prevents the conception of a pregnancy. This temporary authorization has been reapproved multiple times, but Congress has always stopped short of permanently authorizing it and expanding the types of ART provided to veterans. While PVA is grateful for these provisions, it is time to permanently fund these treatments and include infertility as part of the regular medical service package offered by the VA.

In August 2023, the National Veterans Legal Services Clinic at Yale Law School filed a lawsuit against the DOD and the VA challenging IVF policies claiming they were unlawful. Current policy states that only veterans with a service-connected infertility diagnosis, or their spouse, are eligible to receive fertility treatment through the VA, but only if the veteran was able to produce their own genetic materials (sperm/egg), and only if they were married to someone of the opposite sex.

In January 2024, DOD announced the department was proactively making changes to the existing policy by abolishing the ban on donated genetic material and eliminating the marriage requirement to access IVF services. Days later, the VA put out a press release stating an intent to do the same. While PVA commends both DOD and VA for reducing access barriers to IVF, we will remain cautious until the VA releases the policy change for review. We urge the VA to work with external stakeholders in drafting the new policy to ensure that more veterans are eligible to use the benefit and to avoid exclusionary language that might impact eligibility.

These are great first steps towards ensuring that veterans can access IVF services at the VA, however, a service-connected disability is still required to receive this benefit. Infertility is a difficult experience that can often take months or years to diagnose, and proving service-connection is even more difficult. PVA believes that infertility should be another diagnosis included in the medical benefits package offered to covered veterans through the VA. To improve access to fertility services and ensure that all veterans can receive treatment if they receive an infertility diagnosis, Congress should pass the Veterans Infertility Treatment Act (H.R. 544) or the Veteran Families Health Services Act of 2023 (H.R. 5492/S. 2801), which would allow appropriate infertility treatments to be authorized as part of the medical benefits package.

Chairman Tester, Chairman Bost, Ranking Member Moran, Ranking Member Takano, and members of the Committees, I would like to thank you once again for the opportunity to present the issues that directly impact PVA's membership. We look forward to continuing our work with you to ensure that veterans get timely access to high quality health care and all the benefits that they have earned and deserve. I would be happy to answer any questions.

Information Required by Rule XI 2(g) of the House of Representatives

Pursuant to Rule XI 2(g) of the House of Representatives, the following information is provided regarding federal grants and contracts.

Fiscal Year 2023

Department of Veterans Affairs, Office of National Veterans Sports Programs & Special Events — Grant to support rehabilitation sports activities — $479,000.

Fiscal Year 2022

Department of Veterans Affairs, Office of National Veterans Sports Programs & Special Events — Grant to support rehabilitation sports activities — $ 437,745.

Disclosure of Foreign Payments

Paralyzed Veterans of America is largely supported by donations from the general public. However, in some very rare cases we receive direct donations from foreign nationals. In addition, we receive funding from corporations and foundations which in some cases are U.S. subsidiaries of non-U.S. companies.

ROBERT L. THOMAS JR.
PVA NATIONAL PRESIDENT & CHAIRMAN OF THE BOARD

PVA has changed my life by introducing me to things that I believed to be over when I became injured, such as the National Veterans Wheelchair Games, and showing me that you can still live a fulfilling life although you have sustained a catastrophic injury.”

Robert Thomas grew up in Cleveland, Ohio and played football and basketball. He enlisted in the U.S. Army shortly after graduating high school in 1987. Thomas served as a power generation equipment specialist at Fort Sill, Oklahoma; Camp Humphreys, South Korea; and Fort Bragg, NC. While on active duty, in 1991, Thomas had a diving accident that severed his fifth and sixth vertebrae. He was introduced to PVA through the Cleveland VA Medical Center. PVA helped him navigate his new life by working to obtain his earned benefits through the VA, and reintegrating him back into society through social outings with the recreational therapist.

Thomas joined PVA in 1993 as a member of the Buckeye Chapter of PVA in Ohio, and a little while later, began volunteering with the chapter. He took some time off to earn his associate degree in Information Technology, and returned to the Buckeye Chapter of PVA board in 2010. He served as the chapter’s vice president from 2012-2015, and as the chapter's representative on the national Field Advisory Committee and the Resolution Committee.

Thomas was elected as President of PVA May 2023 during the organization’s 77th Annual Convention, to begin a new, one-year term on July 1, 2023. He initially joined PVA leadership at the national level in 2015 as the parliamentarian, and was elected to serve on the Executive Committee in 2017.
Thomas continues to serve PVA because he wants to help lead the organization well into the future. “My inspiration to serve stems from PVA’s past and present leadership,” Thomas says. “Being a member for 30 years and seeing how unselfishly each leader, member, employee, and volunteer gives of themselves makes me want to continue to serve an organization that does so much for veterans and the disabled community.”

In addition to serving as President of PVA, Thomas currently serves as the chair of PVA’s Education Foundation. He was also appointed to the VA’s Family Caregiver and Survivors advisory committee. Thomas and his wife, LaShon, live in Macedonia, Ohio. Thomas enjoys reading, watching sports, and playing adaptive sports like power soccer, bowling, air guns, and scuba diving.